Developmental Disabilities

Residential Study Advisory Council Meeting Notes

December 15, 2005 (9:00 am-3:00 pm)
Seattle Sea-Tac Hilton

Council Members Attending: Dale Colin, Greg Devereux, Lori Flood, Marcy Johnsen, Kathy Leitch, John Mahaney, Lance Morehouse, Karen Ritter, Senator Dale Brandland, Senator Adam Kline, Representative Brendan Williams, Representative Jan Shabro, Kari Burrell

Staff Members Attending: Sharon Swanson, Jonnel Anderson, Chelsea Buchanan, Amy Hanson, Donna Patrick, Tom Lineham, Steve Masse, Don Clintsman, Gaye Jensen, and Facilitator Marge Mohoric

Guest Staff Attending: Chris Olsen, Bob Hubenthal

Meeting Purpose:

1. To complete the data-gathering phase
2. To approve the concept, outline, and recommendations for the January 1, 2006 Report
3. To determine next steps for the Council and staff

Chris Olsen & Bob Hubenthal--RHC Capital Needs

- Refer to PowerPoint presentation
- Questions/Clarifications
    1. Request for list of members on the Asset Management Advisory Committee
    2. Request for information regarding liability awards for both RHCs and the community
    3. Is the DDD Region 2 office a tenant at Yakima Valley? Is there the possibility of additional lease income at any RHC? (See JLARC Report for additional information.) Are there other DSHS services that could be relocated to RHC unused space?

Tom Lineham, Chelsea Buchanan and Amy Hanson—RHC/Community Cost Comparison

- Refer to Handout
- Questions/Clarifications
    1. Do provider rates cover the capital-type costs of the program?

Jonnel Anderson, Sharon Swanson, Gaye Jensen, & Don Clintsman—Emerging Issues

- Refer to Handouts

- Questions/Clarifications

Aging Clients & Aging Caregivers

1. Q: Are there people that we don't know about?
   A: Yes, we assume there are families and clients who are not known to DDD until there is a crisis.

Respite Care

2. Q: Are people coming from the west side of Washington to Yakima and reducing availability of planned respite?
   A:
3. Q: Is there a limit on how long people can stay in a respite care location to be considered respite
   A: Technically there is no limit, so the respite may become long-term care
4. Q: Are all 26 respite beds funded
   A: —The 16 beds at YVS are funded for respite. The other beds at the other RHCs make use of empty beds or unused capacity.
5. Q: What is the wage difference between what people are paid to provide respite in the community and the RHC?
   A:

Residential Rates

No questions

Public Comments—what is the most important recommendation that you would like the Council to make to the Governor and Legislature?

Commenter 1:
I also think it is very important to include the idea of a dramatically shrinking workforce as all of the baby boomers continue to age (a huge number of workers now) and how our system as a whole will change and develop to accommodate the fact that the pot of workers will not be there to do all of the jobs needed. One of the ways that people are currently able to live full lives, participate in their communities and live as they choose is because there are people to assist them in doing so.

Remember, as time goes on, the ones who are providing the assistance & support now are the same ones who will need it later.

Commenter 2:
The WA State Constitution, in Article 13, requires the state to foster and support institutions for developmentally disabled citizens.

DSHS is hostile to RHCs and has failed to foster and support them. RHCs should not be run by an agency unwilling to follow the constitutional obligation to foster and support RHCs.

Commenter 3:
1. Moving people is potentially destructive to the health and behaviors of those individuals. Medically & behaviorally fragile people should be maintained in stable living arrangements & moved only as a last resort.
2. All DDD services have been significantly under-funded for many years.

3. Are there enough RHCs?—are people in Bellingham & Vancouver served by RHCs: a) residences b) respite c) professional services

4. Some significant concerns regarding RHCs are wholly within the scope of DDD policy: e.g., how many residents in a duplex unit (DDD converted Fircrest duplexes' day rooms into double bedrooms so units have 8 residents instead of 6), DDD can provide as many greater community outings as they will for more integration.

Commenter 4:
Private (for profit or non-profit businesses which provide homes/services for DD persons may go out of business at anytime—leaving multiple persons in need of a new home. Whereas, the RHCs offer longer-term stability and need to be considered part of the infrastructure and safety net—as set up in Washington State Constitution establishing RHCs. There needs to be a continuum of services using both private and public facilities.

Commenter 5:
Although each RHC (with the exception of Yakima Valley School) has 2 respite beds, funding is taken from the operating budget of the RHC. The concept of "planned respite" is on the wane. Respite beds are currently occupied by crisis clients. Only after 30 days are the funding functions changed. Crisis respites change the staffing dynamics and claim larger portions of the RHC budget.

Commenter 6:
Advantage of RHC:
1. Continuity of care –24/7
2. Immediate staff response to incidents—medical and behavioral
3. On-going and close observation & monitoring
4. Preventative medical care
5. Expertise in all areas of care
6. College campus environments—freedom to walk about
7. Visiting community medical specialists
8. Comprehensive medical care
9. Community environment

* MULTI-DISCIPLINARY MODEL OF CARE—V.I.P.

Commenter 7:

People opt to live in retirement communities and are not criticized for living there; and there are no groups advocating for their protection against congregate facilities. So, why is "congregate care facility" listed under RHC disadvantages in the Council's list of advantages & disadvantages?

Commenter 8:
The RHC information (given in today's session) that relates to census was not clear that the numbers of residents & the decline in census have been the result of policies either by DSHS or influenced by them. The references to "Trends Toward deinstitutionalization" are therefore, policy driven and not valid bases for dismantling the system as is desired by some in the audience/Council.

Commenter 9:
Of the 7139 people being served, only 1033 in RHCs and 113 in SOLAs have stability in staffing. 5993 have underpaid staff, turnover very high, living wage critical.

Commenter 10:
I fell that its totally unnecessary for people to make remarks against state workers. We care as much as the community does. Remarks like we are here to just protect our jobs. I personally feel that both can work together. To provide the best for all concerned.

I think instead of both fighting each other, we should look at how both can work together to provide the best for these people.

Commenter 11:
Let's open up the services to those in the area—RHCs are more than residential services.

Commenter 12:
$32.2.5 a week is the maximum food stamp benefit for a household of "one". Clients are told by DD case managers to go to food banks. Contract allowance can be available—but 1) is discouraged, 2) funds must be spen w/o assurance that they will be reimbursed.

There is no auditing to determine which agencies use contract allowance—which do not. There is no minimum budget standard for DD clients living in the community. Clients should be allowed to eat every day.

Commenter 13:
Where is mental health represented in this group? DD clients are often dual diagnosed. Community based mental health services are limited with little coordination with DD. DD clients are the "poor" stepchild of the mental health system which right now appears to be co-occurring disabilities such as drinking and mental illness.

Commenter 14:

The Advisory Council meeting must not be a secret. Even at the Hilton this meeting was listed as a Governor's Budget Meeting. DD Region 4 did not know about this meeting. I went to 3 hotels trying to find the meeting. Public comment should not be an "annoyance" to the Council, but rather an opportunity to learn what the community thinks.

Commenter 15:
What is missing is clear data on community-based services. When making comparisons, it is very important to address all of the needs and all of the services and all of the costs for people with equal or similar needs.

We need to focus the Council's discussion outside of the box. (The box is the community vs. RHCs and how many.)

Commenter 16:
The question was raised: "Do we really need 5 RHCs?" Then the state and national trends were referenced. RHCs would be better used if they were made available without the current bureaucratic resistances.

Commenter 17:
It was mentioned that RHCs can mean some degree of isolation from the community. Many people living in the community find themselves extremely isolated, watching TV with no other activities. RHC residents have active programs. How can we provide what is available in RHCs for more people?

Commenter 18:
Children can be admitted to RHCs by "exception-to-policy".

Commenter 19:
Can we ask for supplemental money so we can have a credible study? A credible study would have to be done out-of-house by a neutral agency. It should be thorough and look at all facets of the services available and needed and by what levels of clients and the costs.

Commenter 20:
Please, lets not just accept that one venue is better than another just because it is community-based or RHC. Let's look at the qualities & services that are needed by the full spectrum of people with DD—then evaluate the placement or service (availability) relative to those. Then let's take "apples-to apples data" comparing like people and design a range of services to meet as many underlying needs as possible with the $ available.

Commenter 21:

A comprehensive needs analysis should be conducted, including client well being: activities, family/support and relationships, environment, professional supports, ed. supports, and safety: from harm, incentives to keep clients safe.

Commenter 22:
The Supreme Court Olmstead Decision has been cited as a reason for moving people out of RHCs. This is a misuse of Olmstead. Olmstead held that for some people, RHCs can be the least restrictive setting & some may belong in such settings for their whole lives. The challenge, in either setting is to provide the supports required by the individuals' needs.

Commenter 23:
State employees are paid an average of 59% more in wages and benefits—no wonder they oppose closure. Apples to apples, all positions in community in same ratio. You must address that inequity! Parents are afraid for one because average turnover in community is 43.3% (2004) while SOLA (state wages) is 4.5%. Frontline community staff turnover is 49% while state employees are 4.6%

Commenter 24:
Must develop more respite options in community. Need more specialized medical and dental services in the community. Need $ to develop housing options in the community.

Commenter 25:
The Arc of King County urges consolidation of the institutions and ultimate closure.

Funds gained from consolidation must be added to expand community-based services

Families occasionally resort in desperation to respite in RHCs because there is no other choice—lack of community and in-home services

Commenter 26:
I am concerned that by only comparing cost of care of RHCs/community-based on the proviso, that you are only focusing on the high need and miss the broader question of "what is the preferred system". We must look at all the needs.

Commenter 27:
In response to the statement about profit vs. non-profit community programs, non-profit agencies must solicit donations to supplement costs and for profits are very limited to the amount they make and all are under funded!

Commenter 28:
Please consider changing RHCs to primarily respite and crisis care and only residential if all other options are unsuccessful.

Commenter 29:

Bottom line: if needs can be met in either an RHC or community setting. . .where would you rather live?

Commenter 30:
It is alarming to hear the presentation regarding the anticipated capital expenditures necessary to upkeep the RHCs in the next ten years. How many individuals currently "unserved" could be served utilizing this $65 million?

Commenter 31:
Based on current choices being made, the #1 choice is people live with their families. The #2 choice is community residential support services: supported living and group homes, Medicaid person care, and adult family homes. These seem to already be the preferred services.

Commenter 32:
We have enormous capacity in the community for anyone in an RHC presently. We have homes in which people live who have as severe disabilities and challenges as any person currently in an RHC.

We serve extremely medically fragile people in the community in health and safe and beautiful homes. We also support people with extreme behavioral challenges to have great lives.

Commenter 33
It seems ludicrous to me that we serve so few people and such high cost when there is the technology, ability and capacity in the community at a more reasonable cost. Additionally, people residing in RHCs deserve and have a civil right to live as a member of a community with roommates of their (or their guardian's) choosing in a "home". People should not be isolated and excluded in RHCs.

Commenter 34:
Lease land long-tem to non-profits that develop 3-4 bedroom homes for people with developmental disabilities and help build homes or small apartment units that integrate all kinds of people to live together—all the units could be HUD subsidized to afford real homes to all kinds of people to live together.

Commenter 35:
Would you choose to live in a RHC—is it your preferred place to live? Live there for a month and tell me you prefer this over your current home. . .

Commenter 36:
I would like to see the Council provide recommendations to the Governor and Legislature as to how to begin addressing the unmet needs in the community as it works to decide how many institutions our state should keep open—not to delay meeting the need for community-based services while it deliberates what to do about the institutions.

Commenter 37:
1. Why must people live at the institution to access specialized services only available there? Why can't they have access when they need it and when they don't they can go back home?

2. At our agency, the staff know that they don't work for me or for the state but directly for the person needing support. Their job is to assist so they can do anything they choose to do.

3. We have made it our lifelong mission to encourage people to take charge of their lives and to choose what they want to do, what they want to eat, who they want to be friends with and who they don't.

4. When I was in second grade my grandparents opened a group home and 14 children with developmental disabilities moved in. My aunt and uncle were the house parents and my mom was the weekend houseparent (with her 5 girls). All of our vacations and holidays were with all of us from 1972 through the day the group home closed and they all moved into their own homes with supported living assistance.

5. As a child I did not know the case histories of the people that came to us, but I did know that we saved them from somewhere they did not want to talk about or return to. I also know there were more people that wanted to move into the community and I wondered why were they chosen and others weren't?

6. Now as an adult (running a supported living agency), I know the reasons were varied. But, I have been checking and for every person still living in the institution, there is someone in the community with the same or more serve needs being met at the same competency level with one big difference: they choose how they are going to spend their day, what they are going to eat, and who they are going to spend their time with.

7. So, how many states have no institutions left? We are one of the last to update our system to one that is more respectful of our DD citizens.

Commenter 38:
This is a request that all materials that have been submitted and are submitted in the future to this council be included in the public, electronic record. Reasons:

1. To the extent that only the official point of view that is presented to the council can be authorized for electronic inclusion, the process is biased. Documentation of opposing points of view is what makes a process transparent. Not having the material as part of the electronic record in the context of the meeting notes and materials makes it less likely that anyone will ever read it, especially busy legislators who are not part of the process.

2. People are too busy to have to wait for ancillary material to come in the mail. Refusing to include it in the electronic record virtually ensures that it will never be assimilated in context, if at all. So this becomes an effective way of screening out undesired testimony.

3. Also, because in this day and age, what survives as part of any record usually is the electronic record, to refuse to include it electronically puts public testimony that does not fit on the cards at risk of being lost from the record. And the process ceases to be transparent! Action for RHCs and Friends of Fircrest

Council Discussion

1. **The mission of the Council is to "identify a preferred system of residential services". What are the strengths and weaknesses of each component below in the current residential system in Washington?**

Brainstorm follows:

System Components	"Strengths"	"Weaknesses"
Eligibility Determination Process	• DDD came out with 4 eligibility processes customized to age—better than basic birth to 18 • Nice that we are seeing continuity between regions	• Definition rules exclude some people • Sometimes in rural areas they don't know about DDD and that they can be determined for services • Sometimes it is not timely
Eligibility for Services	• We're standardizing the process and the assessments	• Not enough money to provide needed services • Crisis driven
Assessment Process	• Consistency and standardization • Good data • Case Managers who work to adapt to families' needs	• Care tool does not address behavioral needs • Care tool does not address supervision needs • Care tool based on an aging model that doesn't always apply to developmental disabilities • Disappointing that we still don't have assessment data • Not enough Case Managers • Case Managers felt one individual's functioning

System Components	"Strengths"	"Weaknesses"
		ability had risen so funding decreased—one size does not fit all • Overall inadequate funding that requires us not to have enough Case Managers
Family & Relative Caregivers	• Good that this can happen and stay at home and have people be paid • Families maximize natural supports	• Need for additional respite • Aging parents • Burnout emotionally and physically • Not everyone has families willing and able • Competition between crisis and other respite • This is tough on families, specifically siblings (e.g. higher divorce rate) • Economic impact on families • Abuse and accountability is an issue
Adult Family Homes	• Created anywhere • Good option for some people • Licensed so the state has oversight • Special training is available • Inexpensive • Some homes do provide more than they have to for licensing • Long-term care ombudsman	• Reimbursement rate is so low that the individual running the home uses their personal funds • Rate structure is inadequate • Age of the people with DD (e.g. younger with older) • Not required to offer habilitative services • Lack of liability insurance (not required) • Abuse and accountability is an issue
Group Homes	• Smaller settings in the community • Continuity of staff • Family nature of staff • Habilitative care	• Staff turnover – frequently higher than in public settings • Regulatory environment can be inadequate or under-funded • Abuse and accountability is an issue
Supported Living	• Community based • Small groupings of people	• The interest of private owners vs. not-for-profits (weakness or strength?)

System Components	"Strengths"	"Weaknesses"
	• 24/7 care • Training • People can match up with roommates • Community protection program • Employment opportunities	• Abuse and accountability is an issue
SOLA	• Community-based • State employees with benefits and wages • Stable workforce • Can serve challenging people • Employment opportunities	• One time experiment that hasn't been continued • Abuse and accountability is an issue • More costly
RHCs	• Well trained staff • Multi servicing • Low staff turnover • Specialty care • Provides respite • More protective environment—safe • Employment opportunities • Within a large supported environment there are smaller, inviting homes	• Limiting For Certain People • Can be limitations on choice—e.g. renting out pool/space to others • Large congregate setting • Some would like to see their loved one in a community setting and you don't see that in RHCs • Appears to be more expensive • Capital costs are an issue
Children's Foster Homes	• In the community and under DDD • Foster homes can take in a lot of children that would be living in hospitals, etc. • Good resource for a bad situation	• Under-funded • Nurse delegation (e.g. when a child turns 18) • Lack of support for foster parents
Respite (regular, not crisis)	• Keeping families together • Gives parents a break • Reduces incidences of abuse and neglect • Maintains the stability	• Not enough funding • Not enough respite • Needs to be more flexible to meet families needs • Respite from birth to 13 is tough to find

System Components	"Strengths"	"Weaknesses"
	of placement • Opportunity to provide alternative living options for the person • Can happen in someone's home or in a community or RHC facility	• Not enough qualified providers
Medicaid Personal Care	• Forecasted • Cost effective • Individualized • Allows payment to relative caregivers • Is an entitlement • Helps people to live as independently as possible • Can be pooled	• Assessments may understate need • Not habilitative • Limits scope of services to what staff person is reimbursed for
Home & Community Based Waivers	• 4-tier system is beneficial • Entitlement to services • Allows person to live in the community with supports	• Not enough • Institutional bias—legal presumption • Someone in an RHC is not on a waiver
Crisis respite	• Safety of the individual • Needed service • Provides stabilization • Prevents unnecessary institutionalization	• Not enough • Steals away from planned respite • Communication/coordination is a problem as Case Managers often don't even hear about the options • Hard to staff and to figure out what you need to train for
Case Management	**NOTE: stopped here-ran out of time**	
Accountability		
What is considered a person's home?		

System Components	"Strengths"	"Weaknesses"
Capital Issue		

2. Given what you identified above, what are the three greatest strengths and the three greatest weaknesses of the Washington State residential system?

Greatest Strengths:

- We have a good continuum of care in the state
- Spectrum of care--range of services
- Community based waivers
- SOLA's
- Community based system (except for the RHC's)
- Funding strength that the state has opted to be involved in Medicaid Personal Care
- Increased recognition of the value of training and providing a living wage
- Families are the backbone of the system

Greatest Weaknesses:

- Under-funded and limited access to services
- Some of the choices in the spectrum do involve the giving up of personal liberty
- Potential for abuse and neglect
- Don't feel our state has dealt with the issue of aging caregivers
- Current system—it is evident there is a distinct division within the DD community as to which way we should go
- We haven't gotten past the community vs. RHC divide
- Several people in the audience have presented evidence that the concept of moving away from RHC's is a trend and it seems like we need to perpetuate the current

system and not observe the trend across the nation—we have seen a decrease in population in the RHC's correspond with that trend

3. What questions should the final recommendations address?

- Is there a middle ground here? Is there room for the RHC's to be downsized (e.g. the number of them) but enhance the services they provide and still get more money in the system for those underserved in the community?
- Power and Choice—do individuals have the right to say where they'd like to live?
- State employees as an issue—not sure how we address this. If we downsize, is it possible to move them into a community setting?
- Equity issues between state and non state employee providers—bring everyone else up
- Some people get a ton of services and some don't get any
- Can we focus less on one residential option and more on what is needed for the overall system?
- There are diverse attitudes so we should offer choice and continuum of care—but do we really need 5 RHC's?
- What do people really need? Can we get beyond the schism between the community and the RHC's?
- How do we plan for the future—we must see what will be best in the future—how do we help families plan? What options will be available? What best practices are out there across the nation?
- We need to talk about how many RHC's we need to have—we have delayed in investing capital funds in those campuses; what are our thoughts on all of the capital funds that are needed?
- Planning for the future—it doesn't appear that people are thinking about anything else besides a community-based service; perhaps the future solution should be community-based
- Will our solution add or detract from lawsuits?
- Too often, big decisions are emotion driven and not data-driven; and it would serve the overall community in the long term to know what the real facts are
- Can people working in the community have the same wages and benefit packages as state employees?

4. What does the Council need to do to answer the above questions? Are there different approaches that can be taken?

- We have a certain amount of resources, we do have some funding left (around $150,000 we could use for a study); all of our staff are not available during the Legislative session; only Advisory Council/OFM staff time will be available
- I'd like an independent study to look at options for leasing, moving or renting state space (e.g. University of WA study)
- What happened in those other states where they did close down the RHC's? What happened to the residents?
- Need to look at other states where they've kept the RHC's and expanded services
- Can we close even one institution since there are so many unserved?

- There is a fear of the "domino affect" if even one is closed

January 1, 2006 Report:

Does the Council endorse compiling the information from the staff presentations into the January 1, 2006 Report?

Does the Council have specific recommendations?

Does the Council want to review the report before it is finalized? Best method to do that?

- Yes, comfortable with what we've heard from staff as a preliminary, not as a final report. Council needs to review the report before it goes out.
- The staff has done a superior job these past few months of presenting the necessary information. However, the Council hasn't had enough time to clarify and discuss the information; too often this is posed as a money issue, but it is also an ideological issue that has evolved over time
- I'm ready to make a decision and put cost off to the side
- I don't have the luxury of putting costs off to the side—I'm with the majority party
- Many feel this is a civil rights issue, not a cost issue; it doesn't matter whether community services are more costly if they give greater ability for individuals to rise to their potential; we need to come to a fusion of the virtues of community placement and the virtues of institutions and come to a conclusion that isn't just money-based; I wonder if we couldn't do this better by asking the two main clusters of interests groups, those who want all services in the community and those who want to see no closures in the RHC's; why don't we have the 2 main interest groups get together over the session and come back in April with what they'd like to see done; what if we were to have an agreement or procedural mechanism that we will actually pick one of those choices as the basis for some further recommendation to the Governor;
- Don't want consequences like have happened with mental health
- I hope that we can infuse money into the system
- We need to come together and make some hard choices and recommendations—this has already been put off too much and we've had public input on all of this—do we really need 5 Institutions?
- We have to remember that we need to decide what is the best way to serve those we are serving right now—that is the Proviso we're working under right now
- We must expand the Proviso so that all those with needs are served, including those totally unserved
- People need to understand that unspent capital dollars don't automatically translate into operating dollars for the community
- Concerned about doing a report to the Legislature that doesn't specifically state what the Council could do in the next year that would move this debate further along
- We've only had 3 meetings and that isn't enough time to make decisions; obviously we had a late start; we need facilitated discussions outside of the session and that might present a more constructive starting point for us after session

- Part of the dilemma is that this discussion has gone on forever; if we go back to the stakeholder meetings previously—perhaps we need a framework in the Proviso that directly addresses constraints because of a lack of funding
- Recommend we extend the work of the Council; that we intend to have a meeting after session and that we in the interim will look at coming up with more concrete recommendations based on what we learned over the past few months.
- Recommend that there be conversations outside this room and constructive dialogue outside of these meetings. I'd like to see some recommendations put forth as our meetings have focused on information gathering; we still lack information as to the relative acuity. We have some measurements of cost but we can question some of those cost comparisons. We need acuity measures—perhaps have a study to gain that information. I'd also like us to take the issue of capital budget for RHC's off the table. At best what we can do with those capital budget moneys is to build part of a high school or a new prison. We need to debate about operating budget costs, not capital—but we should stick to debating how to best serve the people in our communities
- It may be impossible to take the issue of capital budgets out of this discussions
- Information is lacking on acuity. This is not about "robbing Peter to pay Paul".
- What do we hope to gain from acuity testing to help us make a decision?
- I'd like us to utilize Council staff time and to have focus groups and find out what people in the community really want
- The real issues are philosophical. If we're going to talk about what's best for people with DD—perhaps a worthwhile things we can do, is to bring studies to the table to look at the value of community inclusion and various options. I've received much updated information from these meetings; but let's look at the best practices around the nation and use that to make our decisions
- Does something have to go the Legislature in January? Need to make it clear that these are discussions, not decisions.
- We haven't come to any decisions. Our January report should review progress but we're not at the point of making recommendations
- What is the role and what are the priorities of government? DDD is one of the core obligations of government.
- All Council members want to review a draft of the report before it is submitted.
- Could there be facilitated discussion during session?
- The Council needs a work plan to move the debate forward.
- We need a framework in the Proviso
- We need a bigger "pie".
- How can we get someone to look at RHC properties for income possibilities?
- Engage professional negotiators to help move forward. (This suggestion was given to staff after the meeting.)

- **Agreement of Council Members to continue the work of the Council into 2006, resume in April, 3rd Thursdays.**